

NOTES AND COMMENTS

MAKE TODAY COUNT: A MUTUAL SUPPORT GROUP FOR THE DYING

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The purpose of this paper is to discuss the aspects of a local chapter of Make Today Count. MTC is a mutual support group for persons with terminal illnesses. Organized in 1974, it is part of what some have called the "happy death movement." This movement seeks to make death more humane and less technological. The paper addresses such issues as reasons of joining, the nature of membership, and the gains for persons who join.

The purpose of this exploratory and descriptive study is to examine Make Today Count as a local manifestation of the movement in contemporary society to make dying more of a humane/moral event and less of a technological one. Make Today Count is a mutual support group for persons with "life threatening" (terminal) illnesses and members of their families. It is part of a larger movement in the society which has been labeled by Lofland (1978) and others as the "happy death movement." This phenomenon... has the characteristics of a social movement defined by Herbert Blumer as "a collective enterprise to establish a new order of life (in this case—death). The "enemy" against which the movement pits itself is the "conventional view of death" which is seen as being a widespread societal denial of death and treating it as a technical event rather than a humane/moral one. This movement is part of the "humanistic-counter culture" which emphasizes the western world's dehumanizing, unemotional, technology dominated, and restricted character. It incorporates *actions* as well as an *ideology*. The *actions* consist of talking about death (mutual support groups); educating about it (courses and seminars); rearranging it (de-bureaucratizing it as in the Hospice concept); and legislating about it (promoting "death with dignity")

legislation). the *ideology* consists of explicit criticism of the "conventional" view of death; belief in immortality based on "scientific" evidence; death can be positive—even a "growing" experience; and death as an occasion for acceptable expressivity of emotions.

I. MAKE TODAY COUNT AS A MUTUAL SUPPORT GROUP

Make Today Count was organized by Orville Kelly, a cancer patient, in 1974. The organization was established in Burlington, Iowa, and now has over 200 chapters nationwide. While local chapters are chartered by the national organization the affiliation could be called "loose." The local units have a steering committee consisting of patients, physicians, nurses, social workers, and death educators. The professional members of these committees tend to be rather inactive in the ongoing work of the local chapter. Facilitators are designated to take care of such matters as preparation for meetings, preparation of brochures, etc.

The following excerpt from a publicity brochure seems to be rather typical of the way that local MTC chapters present themselves to the public including prospective members:

MAKE TODAY COUNT is a non-profit, tax-exempt organization for persons with life-threatening illnesses and/or their families. It is a mutual support group composed of individuals who have encountered life-threatening illness in their lives, either personally or as a family member. We share our experience, strength and hope in order to help each other live each day more meaningfully.

OBJECTIVES:

- To live each day as meaningful as possible—Make Today count.
- To know you are not alone in your crisis.

- To be able to talk to people who can understand what you are experiencing.
- To receive and give support.
- To receive and offer suggestions as to how to cope with particular situations.
- To make professional people aware of our needs.
- To offer continued support to family and friends of our members who have died.
- Methods of treatment are not discussed. (Fairfax, VA MTC)

The bi-monthly regular meetings of the chapter studied for this paper are held at a local hospital and tends to be rather informal. The following is a rather typical sequence of events: introduction, business matters, informal presentation by one of the members, discussion, "free for all" which is open to all subjects including illness related problems, refreshments, and "socializing." The usual length of the meetings is 2 to 2½ hours. The average attendance is around 16 with about one-half of the participants having a life threatening illness and the other half family members of patients (not necessarily those present) and other interested persons.

II. METHODOLOGY

The methodology of this paper results in information which is impressionistic rather than systematic. For three and one-half years the senior author has been involved as a non-patient participant in a local chapter of MTC. During that time, he has served as a facilitator, member of the steering committee, and on the speaker's bureau. Additionally, he was involved in helping to organize a MTC chapter in another city. He has also involved MTC members in classes on death and dying and in workshop

settings for persons in the helping professions. The junior author teaches group work courses in a social work program and has been involved with members of MTC in workshop settings. The authors feel, that while this study results in impressionistic material, it can serve as a useful baseline for future research.

III. FINDINGS

The findings of this study will be organized around the following questions concerning MTC:

Why do people choose to join?

What expectations do joiners have?

What satisfactions exist for the new member?

What gains does membership in the group give?

What is the nature of member participation? Is it similar to or different from that in other types of organizations?

Reasons for Joining

In a broad sense people join mutual support groups for two reasons. First, many persons are frustrated and rejected by the larger society and its institutions, and they have feelings of powerlessness over decisions that affect their lives. Second, the individual in the bureaucratic and technological age is classified, categorized, numbered ranked, and labeled. This has been noted by a number of authors in reference to the dying (Blauner, 1966; Cassell, 1975; Mauksch, 1975; Stoddard, 1978). Both of these reasons are relevant in understanding the Happy Death Movement and more specifically membership in MTC. Much of the discussion at the meetings—formal and informal—has to do with difficulties encountered with hospitals, doctors, nurses, families, and friends in gaining some measure of control over one's care after a diagnosis of terminality. For example, a very common theme is the

difficulty of getting a prognosis from physicians and when a prognosis is "extracted" the difficulty of getting the physician to explain the rationale of treatment. Another theme is the reluctance of families to be open after a diagnosis of terminality. An example of this is the sixty-five year old mother of two daughters in their forties who refused to discuss their mother's life threatening illness with her. MTC is presented to the prospective member as a place where you talk about "anything—no holds barred."

Often, mutual support groups attract individuals who are regarded as or consider themselves to be non-conformists or deviants. One indication of this in MTC is the regularity of testimonies of members who are criticized by their families for attending the group (MTC) where you "sit around and talk about death." It is not usual for family members to accompany the person with a life threatening illness to the meetings.

Here, however, we encounter a feature especially prominent in mutual support groups—the prospective member often must define himself as in need of the help of others. This is very obvious of groups like A.A., Synanon, etc. The dying also affirm their condition by attending and participating in the group. This, in light of the tendency of the dying to deny their condition (Kubler-Ross, 1969).

Self-Selection and Imitation

From the preceding it can be seen that mutual support groups have a high degree of self-selection and self-definition. Persons who join MTC are often in desperate straits. They have been given a life threatening diagnosis and in many cases have begun painful treatments. The "successful" joiner who decides to stay in the group may experience additional emotional pain and self-consciousness, as he or she tells and retells the story of "impending" death. And it is the expectation that persons who continue in the group will tell and retell their story.

Another aspect of self-selection is the large number of patients who do not have immediate family—widows, divorced,

unmarrieds, etc., and who see MTC as a surrogate family. Imitation is often a contributing factor in attaching oneself to a group or forming new ones. Edgar Sagarin (1969:56) has observed that

Any group's existence, let alone its publicity and alleged success, suggests to those in an analogous situation the possibilities and advantages accruing from the formation of similar organizations. Although people are prone to establish formal associations . . . they are more likely to do so when successful precedents have been set.

Also, "doing it yourself" now enjoys a great deal of positive social sanction. The publicity given to MTC nationally and locally has been extensive. For example, a five minute feature on a local radio station on MTC resulted in extensive requests for additional information. The station is now planning an entire series on MTC.

Influences From the Outside

It has been suggested by David Riesman and others that for most Americans, external referees are the most meaningful source of self-esteem and evaluation of one's effectiveness in coping with the problems of daily living. It has also been pointed out that humans have a drive to maintain consonance or harmony of their beliefs, attitudes and opinions. When some aspect of an individual's life is "incongruent," he may seek to reduce the incongruence by reinterpreting the observations about himself to fit the perception held by others; or he may seek to revise these perceptions by joining a mutual support group. In this lies the mutual support group's distinct role in identity (re) establishment.

MTC provides an identity function for members as they are affirmed as "complete" people at each meeting by fellow members. External support is provided through the local chapter's speakers bureau which makes presentations to professional and community groups. The feedback from these groups is overwhelmingly positive and often results in donations to the local chapter. Each meeting provides an opportunity for all to hear such

positive feedback. Persons who may have regarded themselves as quite ordinary are now making "dramatic" presentations about their own dying. A special note is made of community or professional groups which do not respond "appropriately" to the "Gospel" of Make Today Count. An individual with a sixth grade education may find herself making presentations to a college class on death and dying, or even being interviewed on a radio or T.V. program. One of the members who was participating in a workshop for professional persons suddenly found herself being interviewed by a major T.V. station in the state and became the subject of a special on the terminally ill.

MTC then serves the function of supporting an identity and self worth as human beings' face of a somewhat "stigmatized" condition. Further, MTC may serve as a vehicle for identity enhancement.

Dealing With Personal Dilemmas

Mutual support groups attempt to aid their members in finding workable approaches to many personal dilemmas. There are a number of ways in which MTC helps its members in this respect. The "Make Today Count" philosophy helps members come to terms with their life threatening situation. In sum, this philosophy emphasizes that we should live each day as fully as possible since we cannot be certain about tomorrow. This represents an attempt to come to terms with a "futureless" life. This approach is repeated and emphasized at the meetings and in public presentations with a religious fervor.

There is also a profound belief in the importance of talking about one's problems in facing a life threatening situation. While it is usually said that people do not have to talk in the meetings there is a definite concern for those who are not talking about their "condition" after two or three meetings. There is always positive reinforcement for talking except in rare cases of "over-talking." The positive reinforcement may take the form of others in the group saying to the novice talker, "we know that it was difficult for you to tell us about your situation, but we appreciate your willingness to share with us." Able "talkers" will likely

find themselves on the speakers bureau for presentations to the public. Few members turn down the opportunity when invited.

There is also a great deal of mutual exchanging of information between persons with similar types of diseases and treatments. For example, persons on chemotherapy will compare side effects. Also, these persons tend to get together by diseases in the informal part of the meetings. There is a great deal of interaction occurring between the twice-monthly meetings as persons visit or telephone. Further, absent members are inquired about as part of the meetings. These reports have become a somewhat standardized part of the meetings.

Leadership, Participation and Communication

Local chapters of MTC usually are organized by "founders" who are responsible for initiating contact with the national offices and making arrangements for first meetings, etc. Naturally enough, these persons often emerge as the "leaders," even though it is a tenet of mutual support groups that leadership is determined from within. This emergent leadership facilitates the "we group" feeling among members. Contributing to the "we" feeling is a rather pervasive social atmosphere and sanction that passivity is not acceptable.

Groupness is fostered by the norm that members are expected to conform to the standards of mutual helpfulness and cooperation. Status is conferred by personal involvement in furthering the interests of the group. Usually, persons most active in the speakers bureau are correspondingly given a higher status in MTC. There is also a distinction in status between those participants who have a "life threatening illness" and those who do not. One advanced cancer patient said in a joking manner, "... its the kind of status that I could do without."

IV. CONCLUSIONS

While MTC represents parts of the "happy death movement" its impact is currently limited to helping individuals adjust to their dying and family members adjust to their losses. There is

very little effort expended in an attempt to change structures through collective action. Members of MTC would fit into the Happy Death Movement as advocates of talk as therapy and talk as education. It will be of interest to note whether a "political" consciousness will emerge in MTC and collective attempts will be made to change hospital procedures, legal constraints on pain-killing drugs, etc. MTC does appear to be helpful to individuals as they face the ultimate loss—their own life.

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SOCIOLOGY AND LITERATURE: THE DRAMATIZATION OF AN EDUCATIONAL EXPERIENCE

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THE SETTING

The news put me in a state of euphoria. After five years of constant preoccupation with sociological formalities, I happily seized the opportunity to teach a course in "Sociology Through Literature." A few faculty members, classicists by conviction, were very enthusiastic about seeing their Renaissance conception of the discipline being realized within their own intellectual territory. The rest of my colleagues did not seem to notice the humanistic deviation in the curriculum. With all due respect, I was amazed by their indifference. Sociology through literature? In many departments around the country, the issue would have generated ideological warfare. When one tries desperately for decades to gain scientific respectability, it is unlikely that one would allow literary nonsense to interrupt the work of theory construction. The edifice of sociology could not afford any longer romantic forms of appearance, even as an aesthetic (what a word!) possibility. The elaborate schemes of our positivistic rationale succeeded in bringing us status that should not be lost in pedagogical experimentation. Whatever its educational merits may be, it would be unwise to substitute literature for the plethora of sacred material offered ceremoniously by the functionaries in the Comtean church of reason.

So the argument runs, and so most sociologists go around performing the ex officio duties of an authoritative professionalism. That is why I was surprised by my colleagues' apathy. Since the expected doctrinal confrontation did not occur, I started wondering about the state of our field. I knew from that forgotten thinker Pareto that if the guardians with their protective